

YOUR HEALTH AND CARE
INSIGHT INTO ACTION #2



Insight from 11 - 24 April 2020

Published: 29 April 2020



At a glance

We have ...

- Created dedicated Coronavirus information and advice on our website and produced an FAQ that is being regularly updated (latest published on 29 April)
- Asked local voluntary and community groups, including local COVID 19 response groups, to help be our eyes and ears to hear peoples' experiences of health and care service at this time. We've also taken part in virtual group meetings to hear peoples' personal accounts
- Received comments and stories about **pharmacies**, **dentists**, **maternity services** and from **cancer patients**.
- Shared and raised issues specifically around:
 - Continued confusion over shielding and social isolation, as well as concerns around *Do Not Resuscitate* conversations
 - Understanding the changes in maternity support
 - Access to emergency dentists
 - Supply of blister packs and branded medication
 - Learning for post-pandemic working with young people
- This report is being shared widely and with local NHS, Local Government and Community and Voluntary services, so they can hear where things are working well and help them identify any gaps.

Background

The way health, social care and community support operates has been affected by Coronavirus (COVID 19), with non-urgent treatment postponed and face-to-face appointments changed to where appropriate and possible over video links. With public access in our community support limited to avoid the spread of the virus.

For Healthwatch West Sussex, the outbreak has also resulted in changes to our work, with much of our planned public engagement and visits to services paused and a greater focus on providing information and advice to the public and stakeholders and supporting the local response to COVID 19.

However, this does not mean that the work of Healthwatch, to understand the experiences of the public, has stopped.



With a fast-moving response to COVID 19, real-time intelligence for services about the issues the public face is even more valuable. It is also important that health and care services understand the impact these changes are having more broadly - especially when they concern peoples' safety or will have implications once services start to be restored.

Recovery from the pandemic should not be a simple return to *normal*, as there are positive improvements in how people access services and how services are working together.

Where is our insight coming from?

At present, our opportunity to directly engage with West Sussex residents is limited to social media, our website, newsletters and responding to calls and emails via our Helpdesk Team.



We've therefore also asked all Community and Voluntary organisations to be our *eyes and ears* so we can understand the experiences of those they support. Our Eyes and Ears email has been sent to over 400 organisations and groups, with some of these also sharing within their own networks.

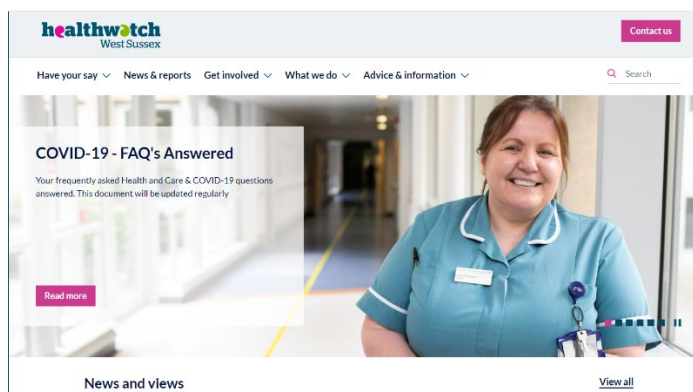
This report is a collation of all these sources of insight.

Advice and Information

Since the Coronavirus outbreak, we have had a greater focus on our information, advice and signposting service, to help people get the information they need from a trusted source.

We have created dedicated Coronavirus advice and information pages on our website for the latest national and local information.

Our Coronavirus web pages for information and advice have had 1,460 views in these two weeks alone.

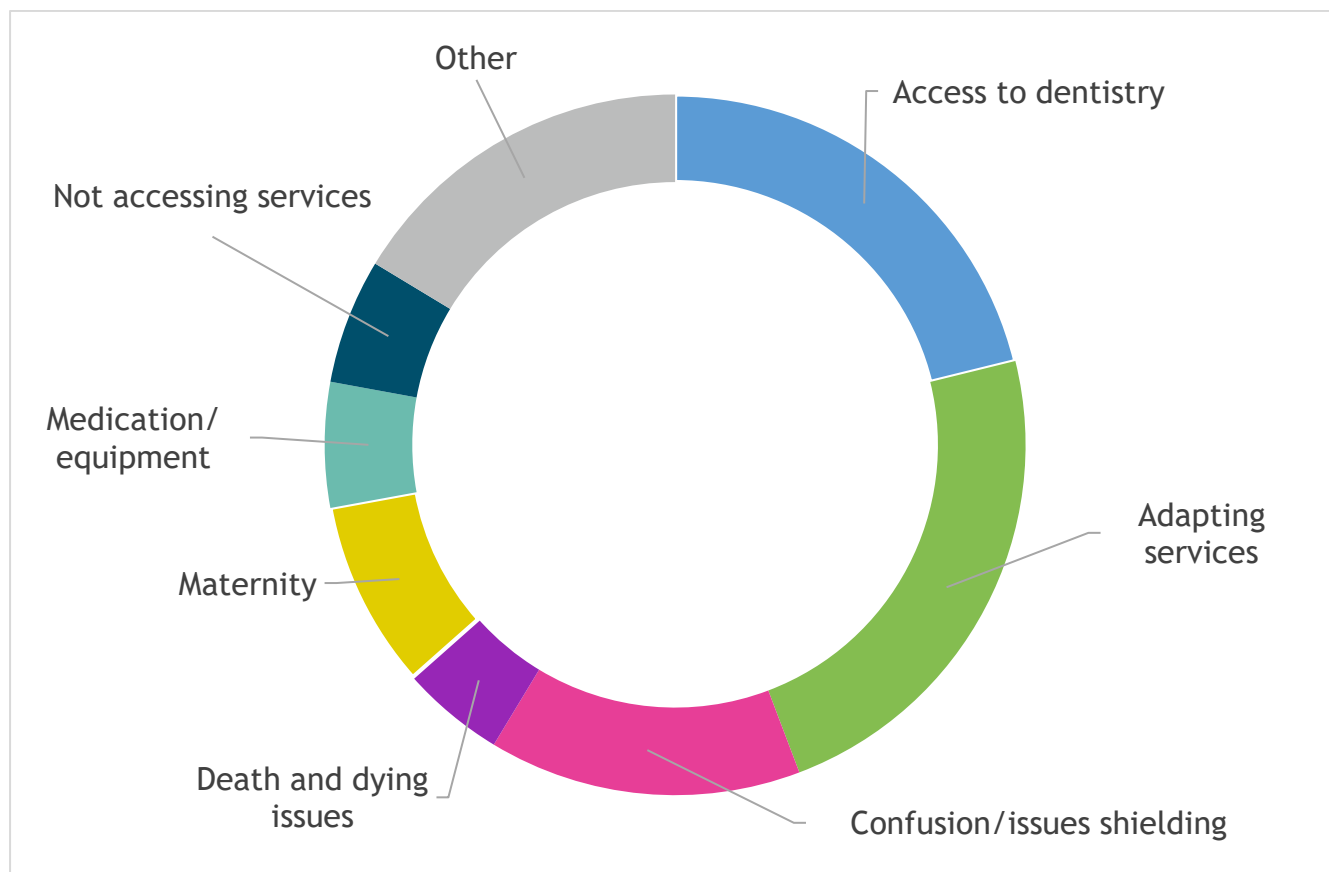
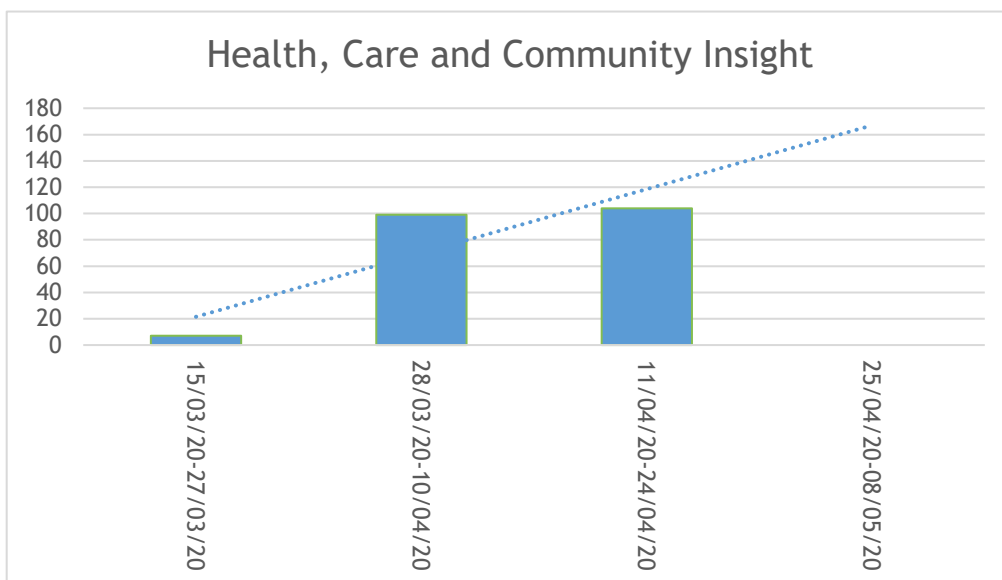


Working with stakeholders and based on what we are asked by the public and community and voluntary sector partners, we also regularly update our [Frequently Asked Health & Care Questions Answered](#). We have been even more active on social media, sharing information and asking for feedback on health and care services. In the last two weeks, these posts have reached 3,708 people directly and been reviewed in many local community group pages.



What are we hearing?

We're producing this report fortnightly to show the public, our partners and those that are accountable for health and care support and services, what people have shared and what has been done as a result. We anticipate this will also demonstrate peoples' changing needs and how services are adapting.





Information & support when it's needed?

Confusing information around how to keep safe

People continue to tell us they are struggling to get the right information about isolating and shielding themselves.



Parent of child with a long term condition shared:

I am so confused. First, they said we should practice '*extended social distancing*', then they said our son was at moderate risk. Now I get the high-risk message which says, '*stay at home for 12 weeks*'. I wish they would make up their minds.

After receiving the high risk message, does this mean our entire household has to stay put? My husband is a keyworker, so at this point I really don't know what to do!

Responses from other residents displayed further confusion.

Many parents were also concerned as they hadn't received letters and were unsure if they needed to talk to GPs or consultants. Many were getting contradictory messages from GPs as to the route to follow.



Hearing from an East Grinstead support group, with members who have medical conditions that fall into the NHS's [Extremely Vulnerable](#) definition, this confusion is very evident:



Support Group lead:

In relation to the Shielding Letters from the Government, which are on Government headed paper, but with the name of a person's surgery at the bottom. Several people who should have had letters haven't received them, so can't access supermarket priority slots, or government food parcels. Two have received letters, but don't know why, as they aren't in the relevant category, so are having to stay in when they shouldn't need to. The surgeries are saying its nothing to do with them -although who else could have supplied the information to generate the letters. There doesn't seem to be a government number to get help.



The information within PM Boris Johnson's letter has further confused some individuals.

Parish councils have contacted us concerned that there appears to be no oversight or way of knowing whether all shielding residents are being cared for or whether some are being *left to perish in their homes alone*.



We know from speaking to people involved in Parish/mutual aid schemes that they are required to submit weekly data of support with their relevant District or Borough Cells/Hub. This suggests that the data is known for where there is robust support, but this does leave the question open as to what is happening in areas where this data is not being collected - so we have asked this question to our locality liaison officer so we can find out the answer.

COVID 19 Community Hub in Mid-Sussex - [Mid Sussex District Council](#) states that the brilliant response for local residents means there is now a waiting list for volunteers to be called on to support others. Other Districts are advertising for volunteers (Horsham District have leafleted this week).

Feedback from a vulnerable adult who has been in contact with another District's Community Hub Team shared that the follow-up information emailed to them came in a PDF document of a spreadsheet that was simply too small and detailed to read. They had fed this back to the hub.

Speaking to Community/Voluntary Organisations, the demand for support continues to come because people are not finding it easy to get the support they need.

Visually impaired residents and other with long term conditions are now struggling with practical things they have previously done independently as they can no longer get delivery slots from supermarkets because they have been excluded from the extremely vulnerable list. However, their sight loss means they are not able to socially distance when out.



If you are struggling with any practical support needs please visit the West Sussex County Council's [Community Hub](#) page.

Our actions:

- We've asked our local liaison officer to find out the pathways for how people can get the support they need, so we can give clear and trusted information and advice and asked again for this information.
- We have raised the question about how the health and care system is assuring itself and others that all shielding and self-isolating residents are being adequately supported.
- Our 29 April published [Frequently Asked Health and Care Questions](#), has been updated to include more information about shielding and how to access support.



Difficult conversation

It has always been very important that people are able to have conversations about their wishes and preferences for their future care and treatment with their GPs and other specialists. GPs are very familiar with having *advanced care planning* conversations, usually with people who face end of life care. These are normally done face-to-face and with patients they know reasonably well.

The pandemic has forced GPs to have these conversations with people who may be less likely to feel they have a reason to face their own mortality (as many have self-isolated and therefore limited their risk of exposure to COVID) and over the phone, instead of in person.

People have shared having *uncomfortable conversations* or receiving *spooky calls* with GPs.



Community organisations shared:

(First source) - Some of my friends have been told to sign Do Not Resuscitate orders and/or told they would not be intubated if they were admitted to hospital. Not being asked their wishes but rather being told and feeling pressurised because they won't be treated anyway. At least two people I know, have said they won't ring the hospital if they feel poorly because they are unlikely to come out alive regardless of the reason they need to go in. These were discussions seemingly not relevant before COVID and appreciate issues about equipment shortages but there are some alarm bells ringing on this.

(Second source) - In general there is a feeling that people over 70 are being regarded as somehow irrelevant and expendable, and that they should just be tidied away. If the suggestion that they should be locked down for another year or longer comes to pass, I wonder if anyone has considered how many places that survive on volunteers would be able to function, as most of the volunteers are retired? All the National Trust sites, for a start, plus charity shops, libraries, community theatres and museums, etc etc. Just a thought.



Obviously, these are not the only reasons people stay away from NHS hospitals and GPs. Simply being able to get to a location is an issue for some - as in the story below:



Female over 70 years shared:

I had a fall and fell heavily on my ankle. The ankle swelled and was badly bruised and painful. I telephoned my GP who said she could not confirm the damage as I needed an x-ray at Worthing hospital. I could not get to Worthing hospital as there are no taxis, buses, and I have no family close by and am also self-isolating. I was also concerned about attending Worthing hospital as this would increase my chances of catching COVID 19. So I decided not to bother and am self-treating.





Our actions:

- We've raised concern over the DNR conversations with the Clinical Commissioning Group and End of Life lead. We've shared our spotlight on [MyCareMatters](#) with a sub-group looking at the needs of support around death and dying. The spotlight details a useful booklet for families and individuals around advance care planning, and we have asked the group to consider the use of these going forward.
- We're currently scoping out a potential project to offer support in this area.



Maternity services

We have access to many of the local mother and maternity social media groups, and through these, we have captured insight from expectant women who are confused about when their birth partner can be with them during labour and the birth. [Information on:](#)



Currently, we can only allow one, consistent, birthing partner present *during active labour and birth*. The birthing partner cannot be swapped for another family or friend during the labour and birth or for the duration of your stay in hospital. They must also be free of symptoms (raised temperature and persistent cough) and have completed any necessary self-isolation periods.

The Sussex Maternity System is developing some FAQs. We've also asked them to look at the virtual maternity tours during COVID produced by other Trusts, as a way of reassuring women that they can still have a positive birthing experience.

Working with our colleagues in the Maternity Voices Partnership we have been made aware that pregnant women are concerned over how they can get to anti-natal appointments when they do not drive or have someone to take them.

Our actions:

- We've asked for clearer information on what 'active' labour means and have included more information in our FAQs about some of the changes to maternity services.
- We've escalated the issue of transport and have asked commissioners to look at extending the eligibility of the non-emergency patient transport service and what other options could be made available to pregnant women who need to self-isolate. We raised this last week and will share responses as soon as available.



How services are adapting?

Access to an emergency dentist

Over the last two weeks we've seen a growing volume of insight from people who are experiencing dental pain or have an urgent need to receive dental treatment, and unable to get through to a dentist. Some were left with no option but to attend A&E.

Here are just some of what we have heard:



Someone in pain posted on social media:

Is it still business as usual for dental practices, I'm in horrific pain and would rather be in Labour to a baby elephant!

People responded: I'm joined to a practice just hoping they are open on Monday - responders gave advice re salt water, oil of cloves etc. They also commented that dentists were emergency only, but some commented that their dentist would see them in an emergency. Others described a process of phone consultations and antibiotics being prescribed.

Resident who is over 70 years told us:

I had a pain in my tooth and phoned my normal dentist which was closed due to COVID 19. A telephone message stated: *contact your GP for advice or 111 if urgent*. I phoned my GP who informed me *to take pain control and it will clear up in a few days*. I had a SKYPE with a friend in USA who is a dentist and he informed me that I needed antibiotics to clear up the infection and stop it spreading. So I phoned 111 and explained the situation and they sent out a paramedic. The paramedic was able to prescribe antibiotics and give appropriate pain control.

The A&E team at Worthing Hospital were brilliant. I've had severe toothache for the past week and due to lockdown, dentists have been shut. I tried ringing my dentist first, but they were useless and said I had an abscess over the phone. I tried ringing them again as the pain was getting worse, and emergency dentists, but no one could help. I tried 111. They gave us several numbers to try, but none of them worked as the dentists were shut. I went to A&E as a last resort as I was in so much pain. They said I had a severe cavity and gave me advice and told me to contact the emergency dental team at Chichester. The emergency dentist in Chichester made me an immediate appointment and took the tooth out. I'm so relieved. It's been awful, so much pain and worry and not being able to get help. Worthing A&E and Chichester were fantastic.



Our actions:

- We've talked to the Local Dental Committee and West Sussex lead and raised questions about access to dental support. We updated our [information and advice on dentists](#) on 21 April 2020 to explain the changes around emergency dentistry.



Getting people support they need

Positive support in a care home: the home staff agreed to administer medication to a gentleman with Myeloma. He and his family were very anxious that he'd have to travel to hospital for the treatment or miss it, but the care home has worked closely with the medical team and is confident that they can deliver the medication (via an implant in his arm).

Positive cancer support: a lady was diagnosed at the beginning of March with stage 2 bowel cancer. She was originally told that they would not be treating her due to the escalating COVID situation. However, after having a scan, it was felt that the cancer could be treated effectively through surgery. She was admitted to hospital and the operation went well. She was back home after four days and is recovering well.

On the flip-side, we heard of a gentleman who has a long history of cancer, which had been treated effectively in the past. He was diagnosed with further cancer at the end of 2019 but was too poorly with other health issues to get treatment. Those issues were resolved. He has been waiting to hear from the oncology team to start treatment. During this time, he has had no oncology appointments and his family are very anxious and scared whether the cancer is progressing. He is in a shielded group due to his previous cancer and other health conditions, but says, *what is the point of shielding from COVID 19 if the cancer proves more of a threat?*

Our actions: We've met virtually with the cancer leads and are working with them to host a webinar for local people to talk through cancer and COVID.

Getting prescriptions and medication

There now seem to be fewer stories and concerns raised around access to pharmacies, but there are a couple of areas we have heard about that are causing issues for residents.

Our actions: We've been speaking to the Sussex Pharmaceutical Committee (LPC) Team on these issues.

Continued access to blister packs



A community organisation supporting people with learning disabilities shared:

Some pharmacies are telling their patients that they are unable to provide blister packs. Initially this was explained as a method to reduce the workload for pharmacies; as per direction from the Clinical Commissioning Group, we supported individuals to ask for *reasonable adjustment*.

However, now the pharmacies are stating that they are unable to provide them due to concerns for cross-contamination. We are concerned as blister packs are an effective way to support the most vulnerable people to remain independent.



We learnt that [Guidance](#) on blister packs has been strengthened during the pandemic.



Some pharmacies are stopping the issue of Blister Packs, as they have been asked to prioritise their time. This is not a blanket “ban”, but availability is being preserved for the most vulnerable who need them the most. This should be after a robust assessment of your need by the community pharmacist. It is the discretion of the community pharmacist to decide if they can support requests for blister packs, taking into account Equality Act 2010 requirements.



If people find themselves in this position and are struggling, we are suggesting for them to have a discussion with the pharmacist so they fully understand their needs and can chat through some alternatives (that may even be more suitable) and reinstate the pack, if needed.

The supply of medication in this way will be reviewed in the future and we’ve asked to be involved in any review/communications so that we can support with inputting peoples’ lived experience to provide a holistic view.

Supplier of some branded medication



A patient told us:

I live with bi-polar and take Depakote (a branded medication). Having been to multiple pharmacies last week (queuing outside each). I’ve been told that they can’t get this at the moment. I’m now to 7 days and this is causing me anxiety. I’m sure there are non-branded alternatives, but I can’t access these as the prescription is made out for the brand name only. I have gone back to my GP to ask for an alternative and have been told a new prescription is being prepared but I’m concerned that that I don’t know what is going to be prescribed and would want to check that it is suitable and approved for my condition and not just Epilepsy (Depakote is also used for Epilepsy). I’ve contacted my Consultant, but they aren’t able to advise as they don’t know what the GP will prescribe. I will pick up the new prescription later and then will be able to check myself that it is an approved alternative for my bi-polar condition.



Some medications can only be supplied as branded items, for clinical reasons, but many can be prescribed as non-branded (generic) items. As the story above shows, getting hold of some branded items is an issue, but the supply of some medication was a challenge before the pandemic took hold.

However, the need for social distancing means people may have to wait outside a pharmacy or come out more times because of the supply issue. **Patients may therefore, want to check with their GPs/Consultant if their medication(s) must be branded or whether the prescription could be for generic medication or supplied in an alternative way if necessary.**



Supporting young people

The Lioncare Group has one aim: to improve the lives and prospects of the children and young people in our care. Their CEO has shared that there is an extremely important issue that this pandemic situation has exposed, that they feel strongly needs to be heard and taken on board by everyone concerned with meeting the needs of children in care.

“ A worker, who had just had a video call with a young person in a children’s home:
When I asked her how things were going under lockdown, her actual reply was, *it’s actually been really nice. It’s felt like all the usual pressure has lifted and we’re all just mucking in and getting on with each other.*”

Lioncare say this echoes what other children in their homes are saying and supports their observation that there is an absolute need to not return to *normal* after the pandemic is over. Instead, they say that ‘we’ (social care for children, society and government) are piling on far too much pressure and demand on the children in our care.

Simply being with the children leads to more effective work and far better outcomes, than making them be everywhere and do everything and meet everyone and say everything all the time to everyone and always.

Community Support Update

Our FAQs are being updated with information on community services and we are working with voluntary and community service providers to support the wellbeing of residents. Together we’ve put forward a proposal to support people who are being discharged from hospital.



How are people supporting good mental wellbeing?

As with shielding, people are confused and interpreting social distancing around daily exercise in different ways. There appears to be a lot of finger wagging, condemning and in some cases, out right nastiness on social media when it comes to how people are going out for exercise.

Wider society's interpreting of exercise 'rules' being you can walk, run or cycle appears to have turned into these being the only accepted exercise and has led to shaming those who would do exercise in a different way - such as daily free-water swimming or walking on the beach (as many coastal residents would do normally for exercise). The insight from social media posts suggests this has left some without the resources that enable them to stay on top of their mental health, and this is obviously detrimental at a time that is innately stressful.

The impact of changes in how mental health services need to operate has had an impact on the care arranged for both the individual and their families. We understand services are working to adapt services and offer support.



A personal story:

Just before the lockdown, a young man exhibiting psychosis left a mental health hospital back to the care of his parents. He had been sectioned late last year and has shown some improvement with medication. He was given significant community and psychological support.

Then came the need to social distance and caused an immediate impact to his care. At home he became non-compliant with his medication and his condition worsened rapidly, so needed a depo. However, the mental health team did not have access to PPE so were unable to administer this in a timely way. It was eventually resolved but this caused a lot of anxiety for his family. In addition, his therapeutic interactions now had to happen by phone and appears ineffective due to his paranoia, which COVID 19 plays into. The young man is said to be switching between not believing it was real, to being very paranoid. Some days he could not be kept in the house, and others he wouldn't leave his room. He became increasingly aggressive, hitting walls and shouting. This has a severe effect on his mother, who had to leave the home and is now staying somewhere else.





11 - 24 April 2020

How this insight will be used?

We recognise that all health and care services are under pressure at this time and have had to adapt their ways of working. We will share this report with the local NHS, local Government and other providers to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps.

Our local mental health, cancer and maternity insight has been shared nationally to inform the discussion at the Health and Social Care Scrutiny Committee taking place w/c 27 April.

For help, advice and information or to share your experience

We are the independent champion for people who use health and social care services. We're here to find out what matters to people and help make sure their views shape the support they need.

We also help people find the information they need about services in West Sussex.



Here to help you on the next step of your
health and social care journey

We have the power to make sure that the government and those in charge of services hear people's voices. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them.



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